

CHILDREN'S HOSPICE AND PALLIATIVE CARE COALITION OF CALIFORNIA

February 2023

Keeping in Touch-

We want to hear from you!

Welcome to our second newsletter! As we ended 2022, the Children's Hospice and Palliative Care Coalition of California hosted a series of small discussion groups to help us determine our next steps. As promised, here is a summary of the discussions and highlights. We want to thank everyone who joined the calls, we had over 30 individuals on the calls, many emailed or called to help us steer our coalition into the future in the best way to meet the greatest needs.

First, It was clear that everyone agreed on the importance of the coalition and the work we could do together, which led to a discussion on how to create and maintain a sustainable coalition. The one recommendation that was repeatedly suggested was a membership-based organization. Although there were several models offered, not one was a clear preference. Sustainability remains a priority and we will be looking for volunteers to help us decide how to move forward towards a sustainable coalition.

Second, Education and Advocacy were strong priorities for most everyone. There were many suggestions on how we could provide education, who to provide education to and what types of education might be offered. We remind all of the Pediatric Webinar series that we co-sponsor; however, our focus during this discussion were focused on our state needs. A repeated suggestion was to use this newsletter as a source of information for PPC in our state. For that we need your help in keeping us informed so we can share the news with our field in California.

Advocacy has always been a strength and focus of our coalition, and certainly, our participants voiced several needs and a strong need to be a priority. We are excited by the opportunities. The challenges with access to PPC is why this coalition was founded over 20 years ago and advocacy remains a priority voiced by all. We may have some more information to share soon.

Third, We have had several offers for volunteers. And we can use your help! If you would like to help produce the newsletter, help us with our website, help us maintain our PPC Environmental Map please email us! And please let us know ways we can let others know about CHPCC, **THANK YOU ALL!**



Resources & Items of Interest:

1. The **AAHPM/HPNA Annual Assembly** is coming up, March 22-24, 2023, in Montreal, Canada! More information can be found [HERE](#).
2. **ELNEC** has several upcoming courses; click on the name for more information.
3. **EPEC- Pediatrics** will be held May 22-24; please, email EPEC.Pediatrics@ucsf.edu for more information.
4. **Join NHPCO on Thursday, March 2 at 3 p.m. ET for Cultural Humility in Pediatric Care, an interactive Project ECHO session** that will explore the importance of providing culturally competent care for pediatric patients and families in hospice and palliative care. Register for the 2023 series or visit the Project ECHO page for more information. Click [HERE](#) for more information.
5. **Courageous Parent's Network** has a wealth of resources for partners, caregivers, and providers. The list is too long to add here so please check out their website by clicking [HERE](#).

Join us at the [CCCC 15th Annual Summit](#)
May 18 & 19th, Hyatt Regency Orange County
We will be hosting a PPC Meet-Up
Meet-Up Information Will Be Shared Soon!

Continued...

Resources & Items of Interest:

6. The NHPCO Leadership Conference will be held in Little Rock, Arkansas. Preconference - September 30 – October 1; Conference October 2-4. This conference is offered in person and virtually. **Call for Proposals will open March 17, 2023.** Please review here for more details:

<https://www.nhpc.org/education/conferences/2023-leadership-conference/>

7. Pediatric Go Wish Together: A conversation game for parents and pediatric caregivers; developed by Meghan Potthoff, Ph.D., APRN-NP, PPCNP-BC, CPNP-AC in collaboration with Coda Alliance. This game is “developed to help parents navigate the unimaginable journey of their child’s illness.” “It is a tool that provides parents and providers a way to think and talk about what’s most important to the child”. More information can be found at [Pediatric Go Wish Together](#)

8. Another great new group is the Child Life in Hospice and Palliative Care Network, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness. They are requesting that interested members fill out a brief survey, sign up today at [CLHPN](#)

9. Registration is open for the NHPCO Interdisciplinary Virtual Conference April 24-26. Click [HERE](#) for more information.

10. The Pediatric e-Journal, a project of the NHPCO, is looking for contributors for its upcoming issues and suggestions for themes for future issues. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com. Upcoming topics:

- Issue #71: Education and Training, submissions due 03/2023; Publication May 2023
 - Issue #72: What do Adult Providers Need to Know. Submissions due 06/2023, Publication August t2023
- Please note that archived issues are available as a community-service by NHPCO and can be found at www.nhpc.org/pediatrics

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Resources & Items of Interest:

11. The National Hospice and Palliative Care Organization (NHPCO) has many **pediatric palliative care resources** available for members and non-members alike, including the longest continuous publication focused on pediatric palliative and hospice care in the US. The current and archived copies and other resources are available at

<https://www.nhpc.org/pediatrics>

12. Recently, the **California Advocacy Network for Children with Special Health Care Needs** announced that their foundation had committed to increasing access to journal articles that may be difficult for family members and non-profit staff to access to improve “effective and equitable systems” as “access to scholarly work is essential to system improvement”. More information can be found [HERE](#). It may be helpful to contact your state’s chapter to determine what resources they may have!

13. The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation have created a community resource to guide families through the funeral/memorialization planning process:

When a Child Dies: Planning Acts of Love & Legacy
This resource is available in both English and Spanish and is FREE, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at [When A Child Dies](#).

14. Have you heard of the new organization **PallCHASE: Palliative Care in Humanitarian Aid Situations and Emergencies**? Their primary ambition is the relief of suffering, and their purpose “To work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies...”. Please visit their website for more information, healthcare professional training and resources in a variety of languages! Click [HERE](#) to check out their website!

HAVE NEWS TO SHARE LET US KNOW!

**Have items of interest to share?
E-mail us at info@chpcc.org**

Please feel free to forward this newsletter!

Are you part of a pediatric palliative, hospice, or supportive care team/organization? Please check our resource map and let us know if your information is up-to-date or if changes are needed. Please contact us via our website <https://chpcc.org> or e-mail us at info@chpcc.org

THANK YOU

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This and future issues of our newsletter will be available on our website and emailed to our mailing list. To join our mailing list or change your preferences, please contact us via our website at <https://chpcc.org> or email us at info@chpcc.org

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2023

Pediatric Palliative Care WEBINAR SERIES



REGISTRATION + INFO:

ppcwebinars.org

12 p.m. PST | 1 p.m. MST
2 p.m. CST | 3 p.m. EST

\$30 individual registration
Discounts for organizations
registering 5 or more people

CE hours available for Nurses
and Social Workers

Additional Info:

info@ppcwebinars.org

- 1.19** **Parents of Children with Complex Medical Needs: Toward an Integrated Behavioral Health Approach**
Thu
Sandra Clancy, PhD | Justine Dellaria, MSW, LICSW
- 2.21** **Compassion, Connection and Creativity: Utilizing Music Therapy to Navigate Caregiver Guilt in Pediatric Palliative Care**
Tue
Lydia Westle, MMT, MT-BC
- 3.16** **Common Problem - Uncommon Solution: Managing Pediatric Pain with Methadone**
Thu
Melissa Hunt, PharmD, BCPPS
- 4.20** **The 5 Ws of Guidance for Pediatric End-of-Life Care**
Thu
Renee Boss, MD, MHS
Jenni Linebarger, MD, MPH, FAAP, FAAHPM
- 5.16** **Caring for a Child in the Community**
Tue
Kristen Moyer, MD, MTS, FAA
Ann Pilarta, MSW, LSW, APHSW-C
- 6.20** **When parents want aggressive treatment for their dying child: How do I respond and where do I turn?**
Tue
Robert Macauley, MD, FAAP, FAAHPM
- 8.15** **Whole Person Care: Looking at the Child Behind the Medical Complexity**
Tue
Dawn Graeme, DPT
Christine Burke, Ms. Wheelchair America 2022
- 9.21** **Blending the Art & Science of Child Life to Foster Choice, Connection, and Agency in Pediatric Patients**
Thu
Korie Leigh, PhD, MPH, CCLS, CT
Jennifer Mangors-Deans, MHA, MS, CCLS
- 10.17** **REALIGN-RESPOND-REPAIR: Responding to Discrimination with your Interdisciplinary Team**
Tue
Kate Ostrander, MD, FAAP | Grace Slater, MD, FAAP
- 11.16** **What is Structural Competency? How Inequality Makes Us Sick**
Thu
Jennifer Matthews, MD

